National Child Death Review statutory and operational guidance: key concepts for practising paediatricians

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Introduction

In October 2018 NHS England published statutory and operational guidance for child death review (1). The Guidance recognises that the death of a child is a devastating loss and families experiencing such tragedy should be met with empathy, compassion, and clear communication. The Guidance aims to put the bereaved family at the heart of the review process: their needs attended to in the hospital emergency department, their hand held by an appointed key worker, their voice heard at the child death review meeting, and their questions sensitively answered by a senior clinician whom they trust. The Guidance is for all health care professionals caring for children as well as senior leaders who commission, provide or regulate children's services. The Guidance covers all children who die less than 18 years of age regardless of the cause of death. It includes the death of any live born baby where a death certificate has been issued, but does not include stillbirths, late fetal loss, or terminations of pregnancy.

The Guidance sets out the key stages of what a good child death review process should look like:

- the immediate actions that take place after all children's deaths;
- the investigations that follow some deaths;
- the local review by those who looked after the child;
- the independent multiagency review by a child death overview panel (CDOP)
- the actions professionals should take in certain specific situations

The process is designed to capture the expertise of professionals through the systematic collection of standardised data to inform local and national learning. Figure 1 sets out the main stages of the child death review process. In the Guidance each stage is covered in detail within a separate chapter. NHS England have published FAQ's related to the guidance to aid practioners in its implementation NHS England FAQs. In this

article we summarise the essential practical considerations that consultant paediatricians and those training in paediatrics need to know about.

Figure 1 Chart illustrating the child death review process

Immediate decision making and notifications

The consultant paediatrician attending the child at the end of his/ her life, along with senior nursing colleagues, need to make a number of key decisions in the hours immediately following the child's death. Table 1 sets out the immediate decisions that must be made and which other key professionals should be involved. As soon as possible the health care team should also form a plan for how best to support the family that will include identification of a key worker and medical lead (see later), as well as a clear explanation of how the CDR process may unfold. In all children's deaths, a set of standard notifications should be made to: the child's GP and other involved professionals, the Child Health Information System, the local CDOP office via a standardised Notification Form (Child Death Reporting Forms) and, in the case of perinatal deaths (22^{+0} week's gestation to 28 days after birth), the lead MBBRACE-UK reporter at the hospital where the baby was born[1], so that national perinatal surveillance data can be collected. Appendix 3 in the Guidance has a proforma for 'Immediate Decisions' that professionals may choose to use. Going forward, it will also be expected that the attending consultant paediatrician will notify the Medical Examiner about deaths not referred to the coroner. The chief Medical examiner was a co-author on the CDR guidance. While arrangements may vary across the region, at the time of writing, it is his intention that local Medical Examiners review of non-coronial deaths will be proportionate and that interaction with professionals and bereaved parents might be via delegated authority. Further guidance on this is likely to be forthcoming.

Table 1 – Immediate decisions to be taken

Immediate decisions	Professional(s) involved in discussion	Context
Should a joint agency response (JAR) be triggered?	On-call health professional for JAR	Arrangements vary widely across the country. The on-call professional may be the community paediatrician, SUDI doctor / nurse, or health visitor. Familarise yourself with local arrangements.
Is referal to the coroner required?	Coroner or coroner's officer	Certain types of deaths meet an automatic requirement to be discussed with the coroner (see appendix 2 in Guidance). In practice, if there is doubt, it is best to discuss the case with the coroner's office .
Is it possible to write a Medical Certificate of Cause of Death (MCCD)?	Hospital specialists and Medical Examiner	It is good practise to agree the wording on the MCCD with the child's paediatrician. Medical Examiners are being introduced across the country. In deaths not referred to the coroner the attending health professional will be expected to discuss the wording on the MCCD with the local Medical Examiner. NHS England are currently liaising with the Chief Medical Examiner regarding expectations arising from the Guidance on the approach Medical Examiners should take with regards to children's deaths
Does death meet criteria for a NHS Serious Incident Investigation or referral to the Healthcare Service Investigation	Hospital patient safety team	Serious patient safety incidents need to be reported within a prescribed timescale. For some types of events the NHS serious incident investigation is the responsibility of the HSIB. HSIB can carry out independent investigations on any child with family consent where there are patient safety concerns and accepts referrals from any source and via the HSIB website. Separately, HSIB investigate cases of intra-partum stillbirth, early neonatal deaths of term babies

Branch (HSIB)?		less than 7 days of age, and severe brain injuries from 37 weeks' gestation where the baby was cooled.
Are actions necessary to ensure the safety of family members?	On-call community paediatrician and safeguarding team	Some types of deaths have safeguarding implications for other members of the family such as siblings.
Are actions necessary to ensure the wellbeing of staff?	Paediatric multi-disciplinary team	Some deaths may be particularly traumatic and may require a planned debrief to ensure the needs of staff are met.
Is a hospital post mortem examination required?	Parents and child's paediatrician	When a MCCD can be issued it is good practice to inform the family of the benefits of a post-mortem examination and what the process entails.
Are other peri-mortem tests required?	Child's paediatrician and hospital specialists	The need for peri-mortem tests should be sensitively explained to the family. In sudden unexpected deaths of infancy/childhood (SUDI/C) local policies should dictate which routine peri-mortem samples are taken. For other types of death (e.g. suspected neuromuscular disease) it may also be important to obtain peri-mortem tissue (e.g. muscle biopsy).

Footnote 1 MBRRACE-UK : Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries . A national audit that collects perinatal mortality surveillance data. MBRRACE is a collaboration which delivers the Maternal, Newborn and Infant Clinical Outcome Review Programme: https://www.npeu.ox.ac.uk/mbrrace-uk

Information gathering and investigations

A standardised data set is collected on all children who die for the purposes of the National Child Mortality Database (NCMD). It consists of a generic reporting form for all

deaths, disease/ condition-specific supplementary reporting forms for some deaths, and a care pathway form that focuses on service delivery. These data will be requested of paediatricians by the hospital's local CDOP either using a paper format or more commonly via an electronic e-CDOP portal.

In some deaths, depending on the circumstances of the case, a number of investigations may follow. These usually run in parallel and vary greatly in time scale. In such circumstances good communication is vital to avoid additional distress to bereaved parents. The Guidance recommends that NHS Trusts should appoint a "case manager", distinct from the key worker role (see below), to ensure there is oversight and co-ordination. These investigations fall into 3 categories: joint agency response (JAR), coronial investigation, and a serious incident or HSIB investigation (Table 2).

A JAR should occur:

- when the death is due to external causes (trauma, homicide, suicide, falls, burns)
- when the death is sudden and there is no immediate apparent cause (SUDI/C)
- when the death occurs in custody or where the child was detained under the Mental Health Act
- where the initial circumstances raise any suspicions that death may not have been natural
- in the case of stillbirth where no health professional was in attendance

In all of these circumstances the attending consultant paediatrician should immediately contact the on-call health professional so as to initiate the joint agency response (as per Table 1). Importantly a JAR should also be triggered if the child is brought into hospital in a moribund state, successfully resuscitated, but then expected to die. This is a common scenario in paediatric intensive care (PICU) where the JAR should be initiated at point of presentation and not at the moment of death, in order to enable an accurate history of events to be taken and, if necessary, a 'scene of collapse' visit to occur.

Table 2 Investigations that may follow some children's deaths

Investigation	Process summary
Joint Agency Response	Detailed guidance for the joint agency response have previously been published and are not repeated in the Guidance. The "Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation (2016)" give comprehensive advice and expectations of all agencies involved in a Joint Agency Response (JAR) (2). All deceased children that meet the criteria for a JAR should be transferred to the nearest appropriate emergency department to enable the JAR to be triggered and the family to be supported. The results of the PM and other clinical investigations should inform the child death review meeting. The child death review meeting should ideally take place before the inquest.
NHS Serious Incident Investigation	Serious incident investigations should occur when it is thought that a detailed analysis (using Root Cause Analysis methodology) of a particular patient safety incident might help clarify understanding of healthcare service delivery factors contributing to the death of the child. They are not designed to explain why the child died. Different levels of investigation may run in parallel and have different time frames and processes attached to them (NHS Serious Incident Framework). The final report from the SI investigation should inform the child death review meeting.
Coroner	Not all deaths reported to the coroner proceed to inquest. The coroner may, as a result of preliminary inquiries, conclude that the death is from natural causes. In such cases the coroner will use a coronial Form 100 A (without a PM examination) or Form 100 B (with a post-mortem examination) to sign the case off to the local registrar as a natural cause of death. If the coroner's duty to investigate a death is triggered he/she will open a formal investigation that will usually lead to an inquest. The inquest aims to determine the identity of the person who died and how, when and where they came by their death. All agencies that have pertinent information (such as records of any internal or joint agency investigation and/or notes from the CDR meeting) are under a legal duty to disclose such information to the coroner

Child Death Review Meeting

The child death review (CDR) meeting is the multi-professional meeting where all matters relating to an individual child's death are discussed by the professionals directly involved in the care of that child during life and their investigation after death. These meetings are already happening but are called by a variety of names in different settings: a mortality and morbidity meeting following a child's death in hospital, a perinatal mortality meeting following a death in a neonatal unit, or a final case discussion following a joint agency response.

However the Guidance does make recommendations in order to standardise practise. While it acknowledges that in certain circumstances it may be appropriate for the review to be quite brief or for the meeting to discuss one child or several children, there is an expectation that all deaths are reviewed and that matters of mortality are discussed separately to those of morbidity.

As occurs now the CDR meeting should generally be held within the department where the child died and chaired by a senior paediatrician or neonatologist.[2] However the location of the meeting might also be influenced by where the majority of the child's treatment took place – for example if a child dies within a few hours of arrival in Hospital A after many weeks of care in Hospital B, it may be wise to hold the CDR meeting in Hospital B with specialist input from Hospital A. The location of the meeting should be agreed between the mortality leads at the two hospitals. What is important is that meetings relating to the same child are not duplicated in separate organisations (e.g. the local hospital and tertiary centre).

CDR meeting chairs should have designated time in their job plan. Conflict of interests should be recognised and on rare occasions, such as when trust between the family and health care team has broken down, an external chair should be appointed. The meeting should ideally take place within 3 months of a child's death, as soon as results of

investigations are available (e.g. post-mortem examination report), but before the coroner's inquest (if there is one).[3]

Importantly, the Guidance advocates that in addition to the health care professionals (doctors and nurses) who usually attend such meetings, some attempt is made to engage with other professionals 'across the pathway of care'; for example, the paramedic, the local paediatrician, and the retrieval team. Experience shows that, *if invited*, such teams make the effort to participate and the conversation will be better informed and the richer for their attendance. Finally there is an expectation that, in every case, an Analysis Form (Panel1) is drafted for the purposes of the NCMD, and for deaths in midwifery units, delivery suites, and neonatal intensive care units, that professionals also use the national Perinatal Mortality Review Tool (Panel 2). The CDR meeting and its Analysis Form output should not be regarded as something apart from the hospital's usual governance processes but as the mechanism by which children's deaths are reviewed.

Footnote 2 The exception to this is following a joint agency response when responsibility for organising and chairing the meeting falls to the 'lead health professional' as per the Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation (2016)

Footnote 3 The CDRM may proceed in the context of a criminal investigation but only in consultation with the senior investigating police officer. The meeting cannot take place if the criminal investigation is directed at professionals involved in the care of the child, when prior group discussion might prejudice testimony in court.

Panel 1 – The Analysis Form

The Analysis Form is the standardised form that we request paediatricians use to record the output of their deliberations at the Child Death Review meeting. The form is an iteration of the previous 'Form C' but clinicans are no longer asked to make judgements about 'preventability' or contributory factors that 'provide a completion explanation for death'. The focus is very much on learning. The Analysis Form has 5 sections: determining the level of influence of relevant contributory factors to the death across domains intrinsic to the child, social enviroment (family and parenting capacity), physical environment and service provision; judging whether any of the identified factors are modifiable (*defined as ones which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths*); categorising the death; identifying learning points and actions; and summarizing follow up-plans for family. The Analysis Form is forwarded to the relevant CDOP, which may decide to amend the CDR conclusions. It is then uploaded to the NCMD

Panel 2 – The Perinatal Mortality Review Tool (PMRT)

The PMRT is a web-based tool which supports standardised, systematic review of care in perinatal deaths. The PMRT should also be used to review the care of post neonatal deaths where the baby dies in a neonatal unit after 28 days but has never left hospital. If a baby is transferred between neonatal units, the neonatal unit where the baby died is responsible for leading the review while ensuring that all units involved in the care during pregnancy, labour and delivery, inform and preferably participate in a joint review meeting. If it is not possible to carry out a joint review then the perinatal mortality review group in the originating unit is responsible for reviewing the midwifery, obstetric and neonatal care provided in their unit before the baby was transferred. In all cases, the review meeting should also generate an Analysis Form which should be sent to the local CDOP. The NCMD and MBRRACE-UK teams are working towards incorporating relevant questions from the reporting and analysis forms into the PMRT so that reports generated will avoid the need for duplicate provision of information by clinicians.

The Child Death Overview Panel Meeting (CDOP)

The statutory responsibilities of CDOPs are set out in the Children Act (2004) and Working Together to Safeguard Children (2018) (3, 4). CDOPs are required to conduct an anonymised secondary review of each child death where the identifying details of the child and treating professionals are redacted. CDOPs are attended by senior representatives across health, police, social services and other agencies, while consultant paediatricians may also be asked to attend to provide professional expertise. Themed CDOP meetings (e.g. Cardiac, Neonatal, Trauma) will also require consultant paediatric specialists to attend. However, in order to avoid a conflict of interest,

paediatricians attending such panels should not be the child's named paediatrician. The CDOP review is informed by the draft Analysis Form from the child death review meeting as well as reports from other professionals and agencies. CDOPs have a responsibility to contribute to initiatives to prevent future child deaths and to provide data to the National Child Mortality Database. The Designated Doctor for Child Deaths is a senior paediatrician who has a vital oversight role for the chid death review process in general and specifically to advise CDOP (Panel 3)

Panel 3 – The role of the Designated Doctor for Child Deaths

The new Guidance no longer refers to "Designated Paediatrician for Unexpected Deaths" but instead to Designated Doctor for Child Deaths. This individual is not meant to be involved in the 'front line' investigation of deaths, but instead to have a vital oversight role for the child death review process in general, and specifically to advise CDOPs in relation to::

- The approach to reviewing the deaths in the area of non-resident children (in conjunction with neighbouring Designated Doctors)
- The setting up CDOP themed panels while co-ordinating with appropriate clinical networks and identifying necessary 'experts' (in conjunction with neighbouring Designated Doctors)
- The appropriate response to the death of a child in an adult ICU
- Assisting CDOP in identifying strategies to reduce child deaths
- Preparation Annual Report

Family Engagement

Parents and carers should be informed about the child death review process and given the opportunity to contribute to investigations and the child death review meetings (Panel 4). In all children's deaths a key worker (Panel 5) and medical lead should be identified. The medical lead should be the consultant paediatrician or neonatologist with whom the family has had most involvement while the child was alive or the designated professional on-duty in the context of a joint agency response. It is good practice that this individual is formally identified after every child's death to support the family. He/ she will need to liaise closely with the family's key worker and together arrange follow-up meetings with the parents at locations and times convenient to the family. The medical

lead (in liaison if necessary with other specialists) should to be able to answer questions relating to the medical care of the child, explain the findings, where relevant, of the post-mortem examination and /or other investigations, and report back the outcome of the child death review meeting. Finally, in deaths where several investigations may run in parallel, NHS trusts should appoint a "case manager", who will support the key worker in having oversight of the various processes, tracking timelines, and ensuring commitments to the family are met. In conjunction with guidance for professionals, NHS England and the Lullaby Trust have published guidance for Bereaved Parents called *"When a child dies: A guide for parents and carers"* (Parent Guide)

Panel 4 – The CDR meeting and the family

The CDR meeting is a meeting for professionals. In order to allow full candour among those attending, and so that any difficult issues relating to the care of the child can be discussed without fear of misunderstanding, parents should not attend this meeting. However, parents should be informed of the meeting by their key worker and have an opportunity to contribute information and questions through their key worker or another professional. At the meeting's conclusion, there should be a clear description of what follow-up meetings have already occurred with the parents, and who is responsible for reporting the meeting's conclusions to the family. This would generally be the 'medical lead': the child's paediatrician, or in the case of a neonatal death, the obstetrician and/ or neonatologist. In a coroner's investigation, such liaison might take place in conjunction with the coroner's office, bearing in mind that the conclusion on the cause of death in such cases is the responsibility of the coroner at inquest.

Panel 5 – Key Worker

The processes that follow the death of a child may be complex. Recognising this, all bereaved families should be given a single, named point of contact to whom they can turn for information on the child death review process, and who can signpost them to sources of support. While it is the responsibility of the organisation where the child was certified dead to identify a key worker for the family, the Guidance recognises that the role could be taken by a range of practitioners. For example: in the case of a child with congenital heart disease the key worker role could be undertaken by the cardiac liaison nurse; in other situations the key worker role may be undertaken by a member of the bereavement support team; and in criminal and coronial cases, the police family liaison and/ or coroner's officer respectively are likely to complement the work of the hospital team. Regardless of professional background the person should be a reliable and readily accessible point of contact for the family after the death; help co-ordinate meetings between the family and professionals as required; be able to provide information on the child death review process and the course of any investigations pertaining to the child; liaise as required with the coroner's officer and police family liaison officer; represent the 'voice' of the parents at professional meetings, ensure that their questions are effectively addressed, and to provide feedback to the family afterwards; and signpost to expert bereavement support if required.

Specific situations

The Guidance additionally gives advice on how to respond to the deaths of children in specifc situations:

- Deaths overseas of children normally resident in England
- Deaths of children and young people with learning disabilities
- Deaths of children and young people in adult healthcare settings
- Suicide and self harm
- Death of children who are inpatient mental health settings
- Deaths of children in custody

We will not give details here on these various scenarios but signpost the reader to the Guidance itself. However the one situation which practising paediatricians may more commonly come across is the death of a 16 or 17 year old in an adult ITU. In these situations Learning from Deaths provides the primary methodology for reviewing the quality of care. It is important though that children who die in adult settings should have the same rigour of review as all other children who die. Hence there should be notification of the child health system, GP, and CDOP office, and there should be close liaison with the designated doctor for child deaths from the outset. The latter should:

- Ascertain whether a joint agency response is needed
- Identify which paediatric professionals should be present at the adult M&M
- Attend the adult M&M for the purpose of completing a draft Analysis form

Summary

The new national statutory and operational guidance aims to standardise existing practise across NHS hospitals to enable the provision of clinically-informed data to influence national health policy. Its essential components reflect, in the main, what already happens in hospitals when a child dies. It was written by paediatricians and

neonatologists who look after dying children in their day-to-day jobs. The Guidance is not intended to be a straightjacket. It advocates flexibility and proportionality. It recognises that local variation in practice will continue; one example of this is when hospitals may choose to have an early abridged review followed by a second review when the PM report is available.

However, the Guidance does require all hospital Trusts and paediatricians to acknowledge their statutory obligation to provide data for the purpose of the NCMD. It also sets certain operational expectations of organisations caring for children: namely the adoption of national reporting and analysis forms; identifying the key worker role; and designating time in professionals' job plans. All paediatricians should be familiar with the essential processes that follow a child's death: immediate decisions and notifications; information gathering; investigations; leading or participating in a child death review meeting; attending a CDOP panel. Below the authors list 6 top-tips for paediatricians to successfully reflect the operational expectations of the Guidance in their hospitals:

1. All consultant paediatricians but especially those in positions of senior management and/or leading clinical governance should read the Guidance.
2. All paediatricians should know who the key contacts are in their locality for the purpose of immediate decision-making (e.g. the on-call health professional rota for the joint agency response, the coroner's officer, the patient safety team).
3. Consultant paediatricians who chair mortality meetings should consider using conference call facilities to enable those key professionals unable to attend the meeting to participate in the discussion. Alternatively they might request them to submit a short report.
4. Consultant paediatricians who lead on matters of clinical governance or who chair mortality meetings should form functional relationships with their local Designated

Doctor for Child Deaths and CDOP manager. The latter may assist with the provision of agency reports for the CDR meeting.

5. Be familiar with the categories of deaths that should trigger a joint agency response (at presentation and not at the moment of death).
6. Participate, if asked, in a CDOP meeting: it will give you an insight into the process from start to finish.

References

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